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# 2019 SPECIAL NEEDS PLANNING GUIDE

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## I. Who Will Care for My Loved One When I'm Gone?

One of the greatest fears that parents and other caregivers have is the possibility that they will die without having arranged for the care of a disabled son, daughter, parent, relative or friend. Most families only have to be concerned about this issue until their children reach an age when they are self-supporting. However, many individuals with disabilities will never be fully capable of self-support, and their parents and caregivers will have to plan for the day when they will not be available to provide assistance and oversight. For these families, the failure to properly plan can cause tremendous hardship for the person with the disability at precisely the time when they need help the most: when the primary source of support, often a family member or close friend, is no longer available for companionship, assistance, and help. **“Future Care Planning”** is the practice of ensuring that services and support will continue for the life of the person with the disability when the caregivers are no longer able to help.

The type and level of assistance that will be needed will vary according to the nature of the disability, the disabled person's age and family circumstances, and many other factors. For example, parents of a minor with a severe developmental disability are often most concerned with identifying a Guardian who is willing to undertake the task of caring for a special needs child. Caregivers dealing with mental illness understand that the illness can bring loneliness and isolation, and they want to ensure that there will always be an advocate willing to step in and assist in a time of crisis. On the other hand, many individuals with disabilities live very independent lives, and need nothing more than some basic assistance in their day to day affairs.

Comprehensive Future Care Planning ensures that the question, *“Who will take care of my loved one when I am gone”* is answered in the most cost effective and efficient manner possible, and in a fashion that considers not only the needs of the disabled individual, but the ongoing financial and health care needs of the caregivers themselves.

## II. Start with a Comprehensive and Honest Assessment

Future Care Planning requires a working knowledge of a broad range of issues: **government benefit eligibility, trust and estate law, estate and income tax rules, guardianship, financial planning, and others.** In all cases, the planner must understand the nature of the particular disability and must have a sense of what the future care and oversight requirements will be. In turn, the care needs will determine the resources that will be required to support a comprehensive care plan.

This last consideration, identifying the level and cost of the services that will be required to provide support to a loved one, is often the most difficult. Indeed, families and caregivers seldom add up the costs of the various forms of support they give to an individual with a disability. Those who contend that a disabled individual's financial needs are minimal often forget to add up the cash value of the many services they provide. They can include serving as advocate, social service coordinator, companion, guardian, chauffeur, money manager, and recreation director. These services enhance the quality of the disabled individual's life. If a parent or caregiver dies without planning for the continuation of these services, the quality of life that the person with a disability previously enjoyed is likely to be reduced substantially.

Some of these “quality of life” services are available through government funded programs designed for individuals for disabilities. Unfortunately, these programs are generally designed only to provide a basic level of support, and the items and activities that make our lives enjoyable, those that truly provide “quality of life,” are simply unavailable. Moreover, the eligibility thresholds for most of these programs are quite low, and living within these thresholds can be difficult. As a result, families and caregivers often seek to “supplement” the goods and services available through these public benefit programs with their own funds, but without jeopardizing benefit eligibility. This is where competent planning becomes critical.

### **III. Elements of a Comprehensive Future Care Plan**

Each Future Care Plan is unique, and it should maximize the formal and informal supports that the individual with the disability receives from government funded programs, family caregivers, community supports, and others. However, all Future Care Plans will contain three basic components: **a legal plan, a financial plan, and a life care plan.**

#### **A. Legal Planning**

The legal planning component of a Future Care Plan will address many traditional Estate and Long-Term Care Planning issues. Has the client considered how the estate will be divided among his or her intended heirs? What is the family’s current estate and income tax exposure? Is there a Will in place, and if so, has it been updated since the onset of the son or daughter’s disability? Will the appointment of a Guardian be necessary, and if so, who will be the Guardian?

What if the *caregiver* needs assistance? Does he or she have a properly drafted Power of Attorney and Health Care Proxy? If aging parents are serving as the primary caregivers for the person with the disability, have they considered how they will pay for *their own* long-term care needs without jeopardizing the inheritance of their children? Does the parent’s Will or Living Trust include a properly drafted Supplemental Needs Trust, which is a trust instrument designed especially for individuals with disabilities? Who will serve as Trustee of the Supplemental Needs Trust? Does the Trustee understand how these types of trusts are to be administered?

What is the functional level of the individual with the disability? Is he or she capable of executing his or her own Power of Attorney and Health Care Proxy so as to preclude the need for a formal guardianship at some future point in time? What are the federal and state benefit programs that support the person in the community, and have the eligibility requirements for those programs been factored into the Future Care Plan?

A sound legal plan will address these and other issues, and as with any type of planning, it is best developed early and in a comprehensive fashion, and with consideration of the needs and intentions of all members of the disabled individual’s circle of support.

#### **B. Financial Planning**

A sound financial plan complements the legal component of a Future Care Plan. Whereas legal planning primarily involves the preservation and transmission of wealth, financial planning is primarily concerned with the enhancement of wealth and the selection of assets to ensure growth, diversification, liquidity and availability to meet a client’s goals and objectives. The two

areas are closely intertwined, and a comprehensive Future Care Plan will contain components of both disciplines.

Consider, for example, a family whose primary asset is the family home. Many families hope that the value of the home will be available as an inheritance for a disabled son or daughter and other heirs. Indeed, many parents and other caregivers contemplate that the disabled son or daughter will be able to continue to reside in the home after they are gone. But have they considered what will happen if *they themselves* reach an age when they will no longer be able to reside in the home and need assistance with their own health care needs? If the caregivers have not considered how *their own* long-term care costs will be met, there is a risk that the home would need to be sold to satisfy these obligations, and may never be available for the son or daughter. One solution may be to use other assets to generate the income that would be necessary to pay these costs. Another possibility may be the purchase of a long-term care insurance policy. In the end, the most appropriate planning route may be to restructure assets so that these costs would be paid for through the Medicaid system. Legal and financial professionals participating in the development of a Future Care Plan should expect to share their ideas on the pros and cons of each strategy, and arrive at the most appropriate solution for the family.

More traditional financial planning considerations include planning to ensure that a family will have sufficient funds for a comfortable retirement, investing in assets that will minimize income tax liability, and consolidating assets to minimize the cost and effort of overseeing a diverse portfolio. These issues are best addressed with a competent and knowledgeable financial professional who understands the heightened importance of proper planning for individuals with disabilities and their families.

### **C. Life Care Planning**

The final step in developing a Future Care Plan is often the most overlooked. At least in theory, people appreciate the need to address the legal and financial issues discussed above. But once the parents and caregivers are gone and the assets have been protected for the benefit of the individual with the disability, many questions still remain. “How should the funds that the family has worked so hard to protect be used to truly enhance the life of the person with the disability?” “To whom should I, as Trustee or Guardian, look to for advice and suggestion when the person with the disability cannot speak on his or her own behalf?”

“Life Care” planning is the process of providing answers to these and similar questions for the family members, friends and advocates who will provide assistance and oversight after the primary caregivers are gone. It begins with ensuring that as much personal, financial, and other pertinent information concerning the person with the disability is stored in a single place and accessible for future reference. Many advocates use workbooks designed specifically for this purpose. The workbooks will usually request background medical information, financial information, family history, community contacts, and recreational preferences of the person with the disability. The workbooks also often request that the caregivers provide similar information about *their own* finances and family supports. This information can prove to be especially crucial for those who must step in and assist when the caregiver is seriously injured or dies unexpectedly.

It is difficult to overemphasize the importance of this step in the Future Care Planning process. Consider this, if you were to get up and leave town today, right this minute, completely unexpectedly and without advance notice to *anyone*, including your disabled family member or friend, who would step in to handle your affairs? Does this person know where all of your pertinent financial information is stored? Have you provided him or her with the legal authority to access your funds and act on your behalf? Who breaks the news to the person with the disability? Who will step in to do what you have been doing all these years? Who stays in contact with the service coordinator or social worker? Who double checks to be sure that medication is being taken as prescribed? Who will make those calls when no one has heard from your son or daughter in days, and who will they call? And if you have someone in mind, have you provided this person with the information he or she needs to carry out your wishes? Does this person know what you know about your son or daughter's needs, preferences and dislikes?

To those people who will step in and assist your disabled family member or friend when you are no longer able to do so, a well written Life Care Plan will be worth its weight in gold. And as uncomfortable as it is for many parents and other caregivers to face the topic, completing this piece of the process often provides the most satisfaction and relief. Certainly, the legal and financial components are equally as critical, but in most circumstances, competent counsel will be able to preserve some of the family's funds for the person with the disability, even if **no planning** whatsoever has been completed prior to the disability or death of the caregiver. **This "crisis intervention planning" is always more expensive, time consuming, and will be conducted before a court as a matter of public record**, but it can be done.

Once the parents or primary caregivers are gone, however, the ability to prepare a comprehensive and detailed Life Care Plan becomes limited. There may be an individualized Service Plan to use as a reference, a dedicated service coordinator who might have some additional personal information, or some other family member or friend who could assist in compiling pertinent information, but none of these fallback references will ever replace the Life Care Plan prepared by the person who has taken care of the person with the disability all of his or her life.

#### **IV. Supplemental Needs Trusts**

Almost all Future Care Plans involve the use of a *Supplemental Needs Trust* (also known as a "Special Needs Trust"). Supplemental Needs Trusts (SNTs) provide a supplemental source of funds for individuals with disabilities. Because of certain legal limitations on these trusts, individuals can remain eligible for government benefits that are based on need, such as Supplemental Security Income (SSI) and Medicaid. SNTs enhance the quality of life of the person with the disability (who is referred to as the "beneficiary" because the trust is set up for his or her benefit). The trust can purchase additional support services, therapy and care that are not covered, or are not covered adequately, by the Medicaid program, but which are vital to his or her well-being. The SNT is the lifeblood of a Future Care Plan which includes management of property and arrangements of personal care, vocational services, housing and case management.

## A. SNTs and Government Benefits

SSI and Medicaid provide a basic level of support for food, clothing, shelter and medical care. The SNT fills in the gaps. Based on the beneficiary's particular needs, the trust can pay for the following, to the extent they are not covered by Medicaid:

- Additional medical treatment or insurance
- Individualized therapy
- Special medical equipment
- Case management
- Recreational activities
- Other goods, services and activities

A supplemental needs trust is **not** counted as a beneficiary's resource for SSI purposes. For purposes of SSI and Medicaid, the trust is not "actually available" to the beneficiary because he or she has no right to demand that the trust pay for any good or services. All distributions or payments from the trust are made at the sole discretion of the trustee, and they are usually made directly to providers of goods and services to the beneficiary. Any money paid directly to the beneficiary will be counted for purposes of eligibility for SSI and Medicaid.

In-Kind donations of food or shelter – that is, when someone (including a parent) gives the disabled individual food, or a place to live for free or at a reduced rate- will generally reduce SSI payments by up to one-third.

## V. Basic Forms of SNTs

There are three basic forms of SNTs. The appropriate type of trusts for a disabled individual depends on whose money or assets will be funding the trust. The amount of money available to fund the trust and whether there is someone who can act as trustee (i.e. administer the trust) are other factors.

- A "*Third Party*" SNT is a trust set up and funded by a parent or other person who has no legal duty to support the disabled individual (parents have a duty to support their children only until they reach age 21).
- An "*OBRA-93*" *Payback* SNT is a trust established by a parent, grandparent, legal guardian or a court, but which is funded with the assets of a beneficiary under age 65. When the person with a disability dies, the State has a right to be "paid back" for medical assistance (Medicaid) it gave to the beneficiary if there are any assets left in the trust.
- An "*OBRA-93*" *Pooled Trust* is a trust that can only be established and managed by a not-for profit organization. A trust account is funded with the assets of the disabled person. With this type of trust, the State does not have to be paid back for medical assistance as long as the beneficiary's remaining assets stay in the pooled trust after the beneficiary dies.

### A. Third Party

These trusts are called "third party trusts" because they are created by a third party – i.e., by someone who is not the beneficiary. In the most common situation, parents will establish an SNT for their child in their wills, which will take effect upon the death of the surviving parent. Caring relatives or friends may also want to set up a trust to be assured that their money is being

used to improve the disabled individual's quality of life, and that it is not causing problems with eligibility for government benefits.

The advantage to a third-party trust is that the parent can use it to provide for a disabled child during his or her lifetime *and* will still be able to direct how any remaining assets should be distributed after the child's death.

As long as the SNT was established when the parent had no duty to support the child and the trust was *not* funded with any property of the child, the State has *no right of recovery and no right to place a lien against the trust property*. In other words, if none of the beneficiary's assets were used to fund the trust, there is no requirement that the State be paid back for Medicaid expenditures upon the death of the beneficiary.

## **B. OBRA-93 Payback Trusts**

This form of SNT must be established by a parent, grandparent, legal guardian, or court and is funded with the assets of a beneficiary who is under the age of 65. The state must be given a right of recovery – in other words, a right to take the assets in the trust when the beneficiary dies – only if the trust is funded with assets of the disabled beneficiary under the age of 65. A person with a disability is permitted to transfer his or her own assets into a qualifying SNT and still receive SSI and Medicaid, as long as the state will be paid back after the beneficiary dies.

Payback trusts are typically set up when an individual receives a lump sum, including an inheritance or the proceeds from a lawsuit or settlement. If the disabled person anticipates large medical bills, the need for lifetime care, or is severely disabled, he or she can use the money to fund a “payback trust” and still qualify for Medicaid and SSI.

The Department of Social Services must be notified when this form of SNT is created or funded, before the trust makes certain transactions, and when the beneficiary dies.

## **C. Pooled Trusts**

By law, pooled SNTs are established and administered by a not-for-profit organization. Individual trust accounts are established by a “sponsor” who signs a sponsor agreement. As with individual SNTs, there are two basic forms of pooled SNTs. Third party pooled trusts are funded with the assets of parents, relatives and/or friends and “OBRA-93” pooled trusts are funded with the assets of the disabled beneficiary.

The sponsor of a trust account funded with the beneficiary's assets can be the person with a disability, a parent, legal guardian, or court. Pooled trusts usually require a minimum amount to set up an account.

The sponsor may also require that after the beneficiary dies, a percentage of the remaining balance will either remain in the trust or be used for other disabled beneficiaries or pass to the not-for-profit agency.

## **VI. ABLE Accounts**

Achieve a Better Life Experience (ABLE) Act (2014)- Federal act provided for 529A accounts for individuals with disabilities to cover disability related expenses. ABLE plans do not



replace traditional trust planning, but provide a useful supplement to an existing plan. Potential uses for ABLE funds include more than just medical costs, including: education, housing, transportation, employment training and support, financial management and more.

Other rules for ABLE accounts:

- For individuals who had a disability before age 26
- Earnings in account are not taxed
- For individuals who had a disability before age 26
- Earnings in account are not taxed
- May receive up to annual gift tax exclusion (\$14,000) per beneficiary for their care
- First \$100,000 is excluded for SSI purposes
- In some states, the Medicaid resource limit in the plan matches the state's 529 Plan (\$375,000 in New York)
- Can roll over 529 Plan assets into ABLE Plan accounts, subject to annual contribution limit
- Has payback provision for Medicaid

## VII. Conclusion

Future Care Planning is by necessity a dynamic process. It is a unique combination of **legal, financial, and care planning** designed to ensure that a disabled family member or friend, including one who has suffered a brain injury, has a system of support and oversight, beyond basic government entitlements, even after the disabled individual's parents or other caregivers become unable to provide care and supervision. Competent Future Care Planning involves a consideration of the needs of both the caregiver and the individual with the disability. A properly drafted Supplemental Needs Trust often serves as the foundation of a comprehensive Future Care Plan. Like any legal document, the Supplemental Needs Trust should be designed to meet the needs of the individual with the disability and should be part of a comprehensive estate and long-term care plan for the disabled person's parents or caregivers.

It is common to hear financial professionals talk about the need to periodically "review a plan" to be sure that it still meets a family's needs. This admonition is equally as important, if not more so, in the context of planning for an individual with the disability, as many individuals with disabilities are unable to actively advocate on their own behalf once their primary caregivers are gone. Laws governing taxes, property rights, and government benefit programs that support a disabled individual in the community are changing constantly. And the resources, needs and preferences of the person with the disability as documented in the Life Care Plan will change with time. The most important thing is to begin the process. Once you have built the foundation, small changes are easy to accommodate. Legal documents can be modified, assets can be restructured, and new information can be added to the Life Care Planning workbook with minimal effort. But if you wait too long to begin the process, you may never have the opportunity to answer the question, "*Who will take care of my loved one when I am gone?*"

At Pierro, Connor & Strauss, LLC, we have the experience and resources to aggressively advocate before the state and federal agencies that administer government benefit programs, and have developed a network of government, private, and non-profit professionals who provide advice and support when a comprehensive "future care plan" is being developed. If you are an individual with a disability, a family member of an individual with a disability.